

HOW WE COPE: AN EXPLORATION OF LOSS THROUGH PORTRAIT AND STORY

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ABSTRACT

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How We Cope is an exploration of the number of ways in which people, specifically young adults, cope with loss due to cancer. Cancer is a disease that, statistically, will affect every human at some point in their lives whether it be diagnosis or the diagnosis of someone close. This portrait project sought to capture the emotion of those who have lost someone close to them following a conversation about the deceased. With research from the National Cancer Institute on the processes of grief and coping, these conversations add emotional context to the varied and circumstantial ways in which people move forward with life after loss. This series aims to provide a compassionate look at these stories while also sharing them via a web platform built for the project.

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EXEGESIS

I. My Project

How We Cope is a project that documents the reflections and emotional experiences of individuals who have lost someone to cancer. The project is comprised of a series of oral histories and photographs. Inspired by the stories of resilience and persistence from friends who have lost loved ones, I wanted to give them a platform on which to share their coping processes and help others find strength in community.

The thesis was also a way for me to explore my curiosity about loss. Loss is an unexpected, albeit inevitable, aspect of human experience. The methods through which people answer unanswered questions and come to terms with reality fascinates me. I lost an uncle to lung cancer and my great grandmother to breast cancer when I was nine. As a kid, my parents often asked me to use their cameras to document various family events because they knew I enjoyed it, and I did a good enough job of it. Today, I have old photographs I took of my uncle, my great-grandmother and other family members I've since lost. That interaction depicted in the photos, between deceased family members and other family members who are still alive, really hit me. These photographs assumed some new emotional value for me—they survived my loved ones in a warm way. The photographs were a vessel in which their human experience was immortalized.

A little over a year ago I lost one of my best friends suddenly in a freak accident. His name was Marcelo Flores. Our conversations consisted of a shared interest in photography, film and storytelling. He was the type of person to talk to strangers and, in a very short time, earn

their trust. He thrived off of these stories and vulnerable experiences with others, and this project is an ode to him and his social technique. His loss showed me the emotional power a medium like photography can have, not only for myself but for other people as well. Although his loss was not cancer-related, it was the engine driving the creative portion of my thesis.

For this project, I drew influence from the rich pool of documentary photography of the past hundred years, and found inspiration in personalities both in front of and behind the camera. In his book *Photojournalism: The Professional's Approach*, Kenneth Kobre (2003) endorses verbal conversation as a prelude to photographic portraiture. “When people become engrossed in conversation,” Kobre writes, “they often forget about the camera, which allows those candid moments in otherwise controlled situations.” As a solution to the camera’s intimidation of the subject, Kobre encourages conversation to mitigate the formality of a portrait session. The most important part of my project was the comfort of the participants. In addition to conversation, I had to be perceptive of differences between their natural body language versus their nervous body language. My ambition was to capture them when they were comfortable—when they were revealing their true self. When interviewing friends, this was easier, of course. The larger challenge was learning and understanding someone I was meeting for the first time in order to represent them and their story in a way they would recognize and appreciate.

Many of the subjects for this project were people I met while participating in a charity bicycle ride from Austin, Texas to Anchorage, Alaska raising money for various cancer-oriented initiatives. My team grew very close, and from these new friendships I began hearing stories of loss to the disease we were riding against. I was curious about the looks in their eyes as they told their stories, some voices changed and some became highly introspective. Some of them avoided

eye contact while telling their stories, and then made a strong connection as they ended, holding my gaze strongly and smiling as if to say, “well there it is.” Others changed the subject when memories felt too intimate or too painful to share. This variation was indicative of their personalities, and I started noticing these expressions in the people whose stories I listened to on the road.

I wanted to try to capture similarly authentic emotional expressions in my photographs. They had to be taken at the scene of the conversation, at the time of the conversation. I wanted to capture the subjects’ faces and posture at the conclusion of their stories, as they were processing both what they just told me and also (maybe) what that vulnerability meant for our friendship. I was merely the “other” in the conversation, the one-man audience. They are the focus, as they are when they tell the story without a camera or a microphone present.

My subjects are predominately millennials who live in an increasingly vulnerable media culture. Popular cultural media are recounting this generation’s stories in incredibly honest ways, and a lot of these stories tackle heavy subjects such as cancer and coping. *The Fault in Our Stars*, both the novel and the film, experienced incredible financial and popular success, and the lesser known but slightly better *Me, Earl and the Dying Girl* finished 2015 on multiple “Best of the Year” lists. Punk musician Michelle Zauner wrote an entire album after her mother died from cancer as a way to cope and be there for her father. She titled it *Psychopomp*, a nod to mythological escorts of souls from Earth to the afterlife, and it saw much critical success. These artists are sharing these stories with necessary vulnerability, whether it be based on their own experience or inspired by the experience of another.

Cancer and grief are public entities for these young adults. Progress through treatments, successes and failures are all tracked through social media posts and pages. Such exposure to these stories can make it confusing for someone experiencing a fresh diagnosis or loss. Are they supposed to process their loss in the same way they've seen characters in film do the same? Are they supposed to have the same process of grief they've observed in their friends' timelines and feeds? These personal processes are meant to be individual, and through my conversations I sought to provide an opportunity for individual expression. There are nuances to this process, external factors that totally shape the ways an event such as death affects a person. Are their parents divorced? What emotional reliance did they have on the person they've lost? How long were they in each other's lives? Circumstances are always different, and I believe that contributing to an ever-expanding representation of various experiences of loss is necessary.

II. Grief and Art Therapy

According to the National Cancer Institute and its PDQ® Supportive and Palliative Care Editorial Board (2017), Grief is a process all humans will encounter at some point in their lives after significant loss—it is intrinsic to the relationships formed with family members and friends. Defined as the emotional (sometimes extended) process of reacting to the death of a loved one, the ways in which one grieves as a result of loss lies in their personality and their personal relationship with the individual they've lost as opposed to some formulaic, agreed-upon recipe of coping. This makes the process inherently dependent on the individual. “The cancer experience;

the manner of disease progression; one's cultural and religious beliefs, coping skills, and psychiatric history; the availability of support systems; and one's socioeconomic status all affect how a person will cope with the loss of a loved one via cancer." (NCI, 2017)

In addition, the NCI (2017) defines bereavement as encompassing the overall emotion of losing a loved one through death. This broad term describes the state of being emotionally affected by a loss, rather than the process of reacting to that loss (NCI, 2017). Bereavement encompasses grief as well as the concept of mourning. Mourning is an outward expression of the inner processes of grief, influenced by the social customs and spiritual beliefs of the mourner (NCI, 2017).

There are multiple types of grief reactions in the NCI's (2017) documentation: anticipatory, normal and complicated. Anticipatory grief precedes the loss of a loved one. It can be felt both by loved ones as well as by the terminally ill patient themselves, preceding their own death. It is during this period that many desire time with the patient to close any unfinished business or to come to terms with the reality of life after loss (NCI, 2017). There are some researchers who disagree and argue that grief is never truly experienced before loss, no matter the amount of forewarning (NCI, 2017).

Normal or common grief is characterized by the ability to maintain normal daily functions while slowly heading toward an acceptance of loss. Researchers have outlined various models of normal grief, including the widely used "Five Stages" taught as denial, anger, bargaining, depression and acceptance (Kubler-Ross, 1969). It is still largely argued (NCI, 2017), however, that the process varies too greatly across the human experience to be modularized in such a way. The main component of common grief is anxiety due to the sudden absence of the

loved one, whether expected or unexpected, leading to a preoccupation with the desire to have this person back somehow. “Normal or common grief appears to occur in 50% to 85% of persons following a loss, is time-limited, begins soon after a loss, and largely resolves within the first year or two.” (NCI, 2017).

Complicated grief encompasses a process comprised of abnormalities in the circumstances arounds the timing of death or abnormalities in the model of normal grief (NCI, 2017). The NCI explains that complicated grief encapsulates absence of grief, delayed grief, chronic grief among others that have a higher potential in causing serious issues such as major depression. They go on to say that treatment is dependent upon the conditions formed and their commonly applied therapy regiments or pharmacological solutions. Maladaptive coping practices in people who have experienced early parental loss is concluded to result in unhealthy coping mechanisms including substance abuse in the future, heightening the need for counseling and outlets for therapeutic expression (Hoeg, 2016). In addition to a traditional therapeutic intervention model in which the patient is assessed and consultations are scheduled, more contemporary means of therapy are being developed (NCI, 2017).

Art therapy is a contemporary form of psychosocial intervention in which primarily visual art skills like painting or drawing are introduced to (in this research summarized by Boelen et al., 2016) the individuals dealing with anticipatory grief or anxiety. Boelen’s survey explains that the patients were exposed to the creative practices of their choice in varying amounts, but focused on the patient’s freedom in creativity with perhaps some ideas given, but largely left to the patient’s devices. “Experiencing this new possibility of expression provided an opportunity for the patients to constructively cope with their disease.”(Boelen et al. 2016).

Whether art therapists worked with the patients on a one-on-one session or in a group setting in the 12 sessions researched by Boelen et al., six papers reported a decrease in anxiety and depression and five found the patient's experienced personal growth through the act of creative expression. In the survey, creative expression as catharsis for cancer patients was found to be effective in improving patient's mental health (Boelen et al., 2016).

Although Dealing With It is not a formal application of clinical art therapy, I argue that the process of storytelling can itself be creative and therapeutic. By selecting a group of people for a project I have conveyed to them that their stories are worthy of being documented.

Sarah Wilson is a Texan photographer who offered her services to The Texas School of the Blind for their annual Prom. She was able to produce not only meaningful portraits for the students and their families, but was able to produce a project worthy of international exhibition, in the U.S. and in China. In a statement given to New Orleans' *Times-Picayune*, Wilson emphasized the particular role of photographs in the lives of these students. Parents photograph the significant moments in their children's lives, and these prom photographs contributed to a "full teenage life" for these blind students. The project is one of warmth and compassion for her subjects, and capitalizes on the simple joy that comes from being photographed at an important milestone in life.

A similar exhibition titled *Nothing Special* is a collection of self-portraits and photographs from around the world created and curated by young people with disabilities. The photographs depict their interests, their passions or their hopes for the future. This means of expression and its subsequent validation (in the form of exhibition) validated their struggle and solidified their space in the cluster of the human experience. (

A subject telling their story, expressing their emotions and sharing their perception of their loss is a way for them to synthesize thought and be recognized for any advancement in acceptance made in their progress through the grief process—which itself has the potential to become difficult and not “common” by varying circumstances: mental health, economic stability, etc. Whatever struggles they might be facing and dealing with, the acknowledgement of such is a step in the right direction.

III. The Documentary Tradition

The pioneers of documentary photography focused on observation as a means of presentation. In the era of muckraker journalism, Jacob Riis did important work in the tenements of New York City. His collection *How the Other Half Lives* is a presentation of life for laborers in the 1880s. His photos were shocking, but his role behind the camera was just as fascinating. The photographs were socially and politically provocative. He was able to “thrill” his viewers. “The beauty of looking into these places without actually being present,” Riis told a reporter in an interview, “is that the excursionist is spared vulgar sounds and odious scents and repulsive exhibitions.” His simple observation inspired those who read him—they didn’t have to leave their bubble to interact with these impoverished subjects. This American interest in the lives of “others” is an important and continuing theme in the American traditions of photojournalism and documentary photography.

Dorothea Lange's photo series for the Farm Security Administration inadvertently set a standard for photographic documentary work. Her portraits of American persistence through the Great Depression have become iconic. Her portrait of the Migrant Mother is arguably the poster for any general education on the Great Depression in American textbooks. It is interesting to note that this portrait is actually posed. In the other photographs of the set, you notice that the children present in the classic photograph are in other parts of the tent laughing and playing. Lange posed them with their heads turned to no doubt create a more somber photograph. The mother's arm and hand are posed in a way reminiscent of classic sculpture, giving her a more intent emotion. Despite the photograph being intentionally set up in this way, its power was felt.

On the other side, candid photography relies on a random energy, the chance of composition falling into place on its own and an even smaller chance of a camera being in the right place and right angle to capture it. Formal portraiture is measured. Composition in staged portraiture is a series of decisions that may involve collaboration by both subject and photographer.

Consider the work of a photographer like Henri Cartier-Bresson, a master of candid photography, in contrast with images created by Arnold Newman, a renowned environmental portraitist.

“There are those who take photographs arranged
beforehand and those who go out to discover the image and seize
it. For me the camera is a sketch book, an instrument of intuition

and spontaneity, the master of the instant which, in visual terms, questions and decides simultaneously.” (Cartier-Bresson, 2014)

Cartier-Bresson based his work around his “decisive moment,” or “the moment at which the elements in motion are in balance. Photography must seize upon this moment and hold immobile the equilibrium of it.” His subjects vary in their interaction with the camera, its presence doesn’t influence their behavior or mar their experience.

Newman’s subjects were prominent individuals, including artists and politicians, usually photographed for *Time* magazine articles. His photographs were composed to include their workspaces (or settings relevant to their work) as reflections of the environment for their portraits. Newman photographed Bill Clinton in the Oval Office, for example.

The two photographers capitalized on their respective styles. Cartier-Bresson was a humanist; he sought to capture human dynamics as they happened to influence social change. Some of his notable work involves running and children. This is Bresson’s decisive moment. Newman, in contrast, has full control over the stage and subject. The critical moment captured in a Newman photograph was the instant at which the his subject revealed their confidence and comfort to a camera with which they are fully engaged.

In both artists’ work, the camera is an extension of the photograph—but not the same appendage in each respective case. Cartier-Bresson’s camera was a voyeuristic eye, catching only the briefest glances of a stranger. Newman’s camera is his eye as well, but also his mouth and his arm. The expectation and anticipation of a photograph is the dominant emotion in his portraits. This works with politicians and various leaders because that dominance makes them

look powerful. Newman's other work includes portraits of musicians and artists in their environment, be it their studios or their homes. Their spaces are extensions of their selves in a sense- messy, orderly or a personal mix of the two.

The work of these two photographers influenced subsequent generations of artists. Cartier-Bresson helped popularize the street-photography movement, used today by professional and amateur photographers often making their money teaching aspiring street-photographers in workshops around the world. I almost participated in one a few years ago with a photographer named Eric Kim. Newman popularized Environment Portraiture and encouraged photographers to see their subjects' common spaces as extensions of their personalities and professions.

Nancy Newberry's (2013) photo essay on the mum tradition at small-town Texas high schools makes use of this environment as extension of persona idea. Newberry explores the homecoming mum as a ritual object for these Texas teens. Newberry has posed her subjects in frozen dance moves or stances accustomed to high school football drill team or cheerleading. The size of a mum is correspondent to the seniority and gender of the student, and the photographs include a diverse cast of high school affiliations. The backgrounds of the photos are striking, showing strong Texan sunsets and the living room decorations reminiscent to anyone who has lived in a small town. These are their environments, the settings for all these traditions and life-moments during their high school years.

I went to high school in this world. These people looked familiar to me and I've met their equivalents in my home town. This photo set stuck with me after viewing and has become one of my favorites. I was able to engage with the photographs due to both the personal familiarity as well as the familiarity she has created for anyone viewing the set. I kept this in mind when

moving forward with my own project, I want anyone viewing the photographs to feel some sense of connection to the work.

Newberry's portraiture is powerful and strange, much like the Texas high school culture it depicts. The facial expressions of her subjects (sometimes tense) don't necessarily acknowledge the camera's presence in the room, they are young and probably insecure in general. Her intent with the project was to simply connect with her past and these people (Newberry, 2013) and I wanted to emulate something similar with my own work- to relay my experiences listening to the countless stories on Texas 4000 and to give those stories that effected me so deeply some audience in the world.

IV. Portrait as Advocacy

The portrait is the dominant force in social documentary photography. Subjects interacting with the camera (even ignoring it) produce the emotion of a photograph. Riis focused on candid work, most likely knowing that the act of staging the portrait of a child laborer would strip the resulting media of the subject's reality. For my project, I knew I wanted something honest. I wanted a collection that felt relatable and engaging to the viewer, like they themselves just had a conversation with the subjects and felt the emotions associated with the matter at hand. I never took a portrait until after a conversation with the subject. I felt that would intimidate them, or set the incorrect tone for the message of the thesis. I couldn't have any walls. I would photograph them either after or during the telling of their stories, when they felt comfortable being vulnerable for me first, and then for the camera.

Riis inspired an ongoing tradition of photography as advocacy. Modern day photojournalism encompasses the idea of telling the stories of a few in an attempt to connect to some larger ongoing theme. The photo of the little boy who drowned while fleeing Syria lying prone on the beach was shocking to the western world. The photo garnered international emotion and has become a symbol for the atrocities not only committed against the Syrian people in their ongoing civil war, but to the struggles they face in leaving their country as well. The photograph incited immediate but short-lived action, “The number of average daily amount of donations to the Swedish Red Cross campaign for Syrian refugees, for instance, was 55 times greater in the week after the photo (around \$214,300) than the week before (\$3,850),” (Cole) Photographers have the power to create content impactful to large numbers of people, but must they in order to be seen as successful advocates, or rather successful vessels for the ideas they seek to represent?

My project does not seek to challenge any political regimes or try to expose any immense social struggles in the way the photographers I mentioned above did. Instead, I want those viewing this project to leave it with a sense of understanding and empathy for the young adults I have interviewed and for the effect that Cancer has on the lives of normal people. I am not trying to provide my own judgements or my own commentary on the ways in which my subjects dealt with their trauma. I instead seek to objectively provide their image and their testimony so that others grieving might find healing in seeing these young people deal with their loss. I want those who haven’t lost someone to cancer to virtually meet those that have so that some general sense of compassion is felt anyway.

V. Ethical Considerations

Cameras intimidate people which is something that impacted my work flow with the project a lot. There's this distinction between the photographer and the camera that logically should be blurred, but exists distinctly in modern culture. There's the process of taking a self portrait, where you as the subject and the photographer have full control over the environment and product. But there's this lack of control in outcome that can put people off. A specific instance of this phenomenon occurred when photographing a friend for the project, she wanted any unflattering picture deleted. This portrait began to border on an entirely staged one because she wanted to control the product- she perceived the camera as an obstacle. I thought the portrait reflected her personality well despite it appearing more formal than the others I took, so I kept it in the project. The situation made me question whether or not I wanted to continue with the candidly formal idea I was basing my creative process off of.

In Philip-Lorca DiCorcia's project, *Heads*, a portrait of a Hasidic Jewish man was used in exhibition. Upon learning of this and seeing his portrait, the man sued DiCorcia on grounds of using his image in commerce and advertising (the photographs hung for sale in galleries). DiCorcia did not ask any of his subjects for permission to photograph them. DiCorcia ended up winning the case, and he argues that his portraits are justified because of the level of surveillance already present in modern city life and the anonymity in which he presented the images. He never talked with his subjects or hid his camera equipment (Dicorcia, 2010).

This is an interesting thought to ponder, do I own the images that I take of my subjects? I created them with property that I own with the permission of the subject. This explicit permission justifies my use of these photographs. It was almost necessary as such vulnerable

conversations, often with friends, were the subjects of the project. To share this material with the world and not let them know would be a betrayal of trust.

How We Cope

Christy



Lost her father to Hodgkin's Lymphoma in 2004.

John



Lost his mother to lung cancer in 2015.

Ria



Lost her father to gastric cancer in 2013.

Arin



Lost her grandmother to cancer in 2014. Her Aunt Cathy is currently battling lung cancer.

Rusty



Lost his father to cancer in 2012.

Sirena



Lost her father to Non-Hodgkins Lymphoma in 2009.

Cecilia



Lost her sister to Leukemia in 2009.

McKay



Lost his grandfather to cancer in 2011.

TRANSCRIBED INTERVIEWS

Christy Goldberg

Right around the time my little sister was born was when we lost our Omi to cancer. I believe she had three types of cancer, but it ended up being lung cancer that got her. She was a smoker but she stopped the day that the surgeon general came out and said that it was known to cause cancer. It's just one of those things has always stuck with me and bothers me about when I see people smoking today. It's like, I lost someone I know and loved and she stopped when she knew it was bad. That was Omi.

Then my dad was first diagnosed with cancer around the time I was born in 1995. He was treated mostly locally. We were in California at the time and I didn't know a whole lot about this story. He was treated, I think he received chemotherapy often with a man who's married to a lady who wrote articles for our local newspaper and so really all I knew about the story was this article and I think she titled it Christina Gives the Gift of Life. It was about how my dad was coming out of cancer and it was all looking good and then I was being born into this family that recovering. I read the article and we didn't really talk about my dad having cancer other than that.

Then when I was in fourth grade, he was diagnosed again with cancer, with Hodgkin's. I remember, I think some of the things that caused him to go back to the doctor were he had kind of a lump in his neck kind of near where a lymph node would be, and then he was having night sweats. My mom now tells me she was pretty frustrated because they took scans and he took

them around knowing something was wrong, and I guess the doctors didn't see anything, but they kept using the same scans. By the time they did another round of scans, then it was pretty obvious that he had cancer.

Hodgkin's is usually a pretty curable type of cancer. I don't know if I was just being protected from it, but I never was really super worried about it because while Omi passed away from cancer and lot of my friends' grandparents did, he was young. He was in his 40s, super strong. He built houses and he could do pushups while I was on his back. He was fit and it was all going to be fine. He would just beat it again. I didn't really understand it.

That was kind of that. He went through chemotherapy locally and he still continued to work. We got more visits than usual from his side of the family, which was fun for us. I was nine. My brother was seven, and my little sister was two at the time. He, I guess wasn't responding to chemotherapy the way that we had hoped, but I guess before that all happened, at the beginning of chemotherapy he started to lose his hair.

I remember one time he walked out of the shower. He just showed me a chunk of his hair in his hand and this is what chemotherapy does and I'm losing my hair. He made the decision that he wanted to shave his head and he knew that I was really obsessed with hair and spent my recesses braiding my friend's hair and cutting ... I love to cut my Barbie doll's hair, and so he let me cut his hair. There's this picture of me, like a white apron and we're sitting on our front deck and I got to shave his head and it was big ... I was so proud. You can see it in my big smile and he was such a good sport about it. It was kind of like a fun event, not a he was losing his hair to chemotherapy as a result of cancer. That was kind of a fun thing for me.

I talked at school with my friends about it. My friend Celia and I, at our daycare, we made this pillow for him and I think it said we love you dad or something on it. We wrote it with just magic marker not really thinking and my dad I think thought it was permanent marker. He went to bed that night with it and he really liked it and then he woke up with his night sweats and he was all upset and he told my mom he was super upset because his sweat ruined the pillow and there was magic marker everywhere. He felt really bad and told me about it. Of course it wasn't a big deal.

Anyway, he started to not respond as much to the chemotherapy. He'd been locally like I kind of said, at this little office. I used to go with him sometimes and I would see the beanies that people left for people and I always thought that was really cool. Sometimes I would go with him. He was supposed to get a scan done or some tests and he wasn't so ... We had oatmeal in the morning and it was really exciting because we were up so early for it. It was this father/daughter date that still seemed fun to me because I didn't really understand why we were doing all of this or how serious it really was. We got to the office and he realized he wasn't supposed to have that oatmeal so we had to go back and he had to reschedule, but it was still a fun day.

At the hospital, CHOMP, Community Hospital of Monterey Peninsula, they have this big koi pond and my uncle and I, during our time there, ended up naming all 50 of the koi fish that were there. I don't know, it was just weird. It was just life in a little different direction, but it just felt like life. Then it was decided that my dad would need a stem cell transplant. He was really lucky and he had his four siblings. He was the oldest of five. They all wanted to see if they were the match. It was this big competition between all his siblings and his youngest sister, my aunt Celia ended up being the winner. She was so excited to be able to help in any way.

He ended up being moved up to Stanford and he was going to be an inpatient there and my parents talked to us a lot about how we were going to have a condo up there near the hospital because we were spending so much time up there. Again, it was just presented in a really cool way. I think there were tennis courts and a swimming pool and it was everything a kid could dream of. We were excited.

For whatever reason, we didn't end up moving up there, but we did spend a lot of time away from fourth grade. It was weird. I didn't go to a lot of school but instead of being at school and hanging out with friends I was in the hospital and drawing pictures for all the patients on the unit. The nurses were my new best friends and I love, love, love, loved them. They were so cool because they were so smart and so nice and so pretty. They really made time to hang out with us.

Things started to take a turn for the worse. My dad developed Graph Versus Host Disease, basically was rejecting the stem cell transplant. It was weird. I remember we had the social worker we were really close with. We had this big family meeting. Our family, because it was my mom's side was all there because they're from the area, and then my dad's side, it was all their siblings and kids. I remember the numbers and the percentages that they gave us, which used to be super favorable because it was Hodgkin's and he was a healthy man, started to be a lot less favorable. Even though I was nine, I really appreciated that my family let us be a part of that conversation because I don't think a lot of families would do that. I remember my uncle, Paul picked me up and I just told him, I said, "I'm scared." He said he was too.

Then I continued to hang out with my favorite patients. My cousin Rebecca and I made pictures that covered my dad's entire wall and then he ended up moving rooms. The hardest part of him moving rooms was having to take off every single painting and every little picture and put

it up, but I was visiting his old neighbor. I forget her name, but she and her sister. Her sister was always visiting. I was in there one day and just hung out in there. The nurse walked me in and made sure it was okay with them. I brought all my pictures that I made for her that day. Her sister was painting her nails and she told me that she gotten me a little present because she knew how much I liked art. During her one allotted time off the unit, because her she was so immune compromised, she went and, or her sister went and bought her a stamp set to give to me and my cousin. We had a new stamp set to use. That was a great addition for our tools for all of our decorations for the unit.

Then I made this bookmark for the nurses. They're in the E1 unit and it said E1 nurses are as bright as the sun. It was a picture and they ended up turning it into a bookmark. In my dad's new room, it became pretty apparent that he wasn't going to make it. I don't remember being super emotional about it. Instead I just tried to use that time. My mom got us some journals and I used one of them to start writing down my favorite stories about times that me and my dad had had. I spent my time doing that and I remember my mom having conversations, especially with my uncle Paul about the funeral and what that was going to look like and what my dad wanted. That was all while my dad was still alive.

I ended up, there was one day middle of November and my dad's ... It was November 19th. My dad's birthday was the 29th and I just really wanted him to make it to his birthday. I was sitting in the hospital bed and reading the story to him of the time that we decided to make dessert together and we just used what we found in the cupboards, which was lemon jello and he thought it would be really crazy and fun to add purple grapes to it. We cooked this lemon jello with purple grapes and it was really terrible and we both hated it, but I just remember laughing in

the kitchen with him and laughing as I read it to him. Then he just stopped reading and his nurse came in and I remember my mom called the nurse in and she was able to pronounce him dead. He was really peaceful and that was kind of it.

That was our family's experience, but I guess I really liked the way that ... If it had to happen, I feel like my family did a really cool job of ... Like my dad would smile his entire way through it. We all stayed together during it. My siblings who fought all the time, I think we behaved ourselves a little better in the hospital than we would have at home and after the fact, our family doesn't really do funerals for the most ... It's a funeral, but it's more of a celebration of life. That was really special and my mom let me be someone that talks during it. My brother, he had some role in it. We both got to do some artwork that was included in the little handout that we gave out at the ceremony.

I remember being at home and trying to write what I wanted to say at his funeral and I ended up talking about how he was the strongest man I knew and he was great and his smile lit up a room and that I now saw him as a star. That's something that I still kind of think about, but I ended my little talk with that he was ... You look up at the sky at night and you see the brightest star, then that's my dad shining down on all of us. Stars have always had a little extra importance to me. My mom sometimes gets me star jewelry, which I love little reminders. Yeah, that was life through nine.

Then after that, I remember waking up sometimes at night or listening to certain songs that made me really, really sad or certain movies. That would make me really upset and I would kind of cry, but never really too my mom. I remember one time she heard me crying at night and she came in and asked ... I think I was listening to a Kelly Clarkson song, but she came in and

asked what was wrong. Yeah, I don't know. It wasn't ... It just kind of, like life went on, but I think, now looking back on it, I think I was just suppressing a lot and didn't really know how to deal with that because most of the people in my community had the two parent family, hadn't dealt with cancer unless it had been a grandparent or hadn't even experienced loss other than a grandparent or maybe a pet.

My family ended up moving from California to Texas, which was great I think for our family, a really good move. We went to a really great public high school, but I remember it being kind of weird because it was like all the families in California knew our family situation and nothing had to really be explained. All the girls on my soccer team were there through it all, everyone at school, all of Lucas' friends. Everyone just kind of knew. Here they didn't and so it was kind of weird explaining it all again and giving that background or just fielding, "What does your dad do?" Kind of questions. Other than that, didn't really talk about him with people.

Then I guess my senior year of high school, or in high school, I kind of made the decision that I wanted to go into nursing mainly because of how much love I had for my dad's nurses. During my senior year I had wrote one of my application essays on why I wanted to be a nurse and it's probably the best paper I've ever written and ever will write because it was something I cared so much about, but I talked about what we went through with my dad and how the nurses were my heroes.

Then that kind of brought forward a little bit more of my emotions and thinking about him a lot, which I think was really good and therapeutic. I started listening to more of the music that my dad and I used to listen to. He had a big truck and so we would listen to ... He loved American Pie and just Morning Has Broken, I think that's what it called by Cat Stevens. Just

songs that I probably was afraid to listen to or wouldn't think to look up, but then now I found a little comfort in them.

Anyway, I ended coming to here, UT - Austin, and had some friends who had lost other people to cancer that I kind of bonded with. They joined this organization called Texas 4000, which I thought was super cool and crazy, but not something I really thought about doing. It just, it didn't really fit my life plan I guess. I guess I had different plans for this past summer, but with a turn of events, a break up and I don't even know what else, decided I was going to apply. I'm so glad I did. I think I actually used the same essay that I wrote in high school, maybe just tweaked it a little bit. I was really excited to get in.

Then it became very apparent that there is this huge group of people that now the conversation was all about loss and it was about cancer and grief and in it that was a big change for me. Took some getting used to, but then slowly became something I was more comfortable with. I didn't really talk about it a lot, but listened to.

Then with the organization we had to give, or were encouraged to give a why ride, which is a presentation and meaning about why we're in the organization and who we ride for, whose been effected by cancer.

I prepped a lot of that because I was really nervous because I didn't know where my emotions would be. I called my mom and asked her if she could send me any pictures of my dad and I. She took a lot of time. I know she went through a lot of albums and I really appreciate it, but I remember she sent some, just when I was younger that I had seen before and put those on my PowerPoint and then I woke up one morning and in my bed here at my sorority house and looked at my phone and my mom had sent some attachments. I opened them up and they were

pictures from the hospital, almost all in masks because we all had to basically scrub in to go into his room because he was so immune compromised and suppressed. I just lost it and was in tears and wasn't really sure if I would be able to tell the full story, but nonetheless I got up in front of everyone and told it, and it was really therapeutic to put it in words, because I haven't done that in a really long time.

That was really the first time I'd told the story, my story, but it felt really good and to have people come up and hug you after, text you about how this effected the way that they look at ... A girl texted me and said it helped her in the way that she thinks about her and her dad's relationship and that she wants to be on better terms with him. Even just that made it all worth it. Then we trained and we trained and we trained and we talked about people that we rode for. It became very apparent that I hadn't just lost my Omi and my dad, but everyone in the room had lost someone and everyone I met had lost someone.

It probably wasn't until the ride that I got really comfortable talking. I had a couple teammates who really just encouraged me to talk and I felt a lot more comfortable. That was when I finally started talking about the really good memories and just the stupid little things that I remember. I felt like just a girl talking about her dad, not necessarily a girl that lost her dad. I didn't have to be sad about it and they were just good, happy memories, which has been really, really cool for me because for awhile I was really scared I was going to lose all those memories which is really sad, especially because with two younger siblings, like I said, Lucas was seven, Nicky was two. They don't have quite as many, so I want to make sure I keep them.

Yeah, that's ... I don't know. I think the ride in Texas 4000 was something that really helped me come to terms with my story and accept my story and accept that I lost people to

cancer, but yeah, that's kind of how ... I think I finally healed this past summer. I feel good about it. Now it's more just how I can use my experience to help others. I went down to Peru in December and did an oncology nurse internship and I'm right now applying to work in pediatric hospitals with the ultimate goal of working in pediatric oncology. I've even looked at the hospital that my dad was treated in as an option down the road.

Yeah, I don't know. It really sucks at times and sometimes I think about how this had been different or I'm graduating in May and how cool would it be to have my dad there, but I don't know. It's life and everyone loses someone at some point. I just try to make it something I build off of and better for.

John

Why did you join Texas 4000?

I started out in this organization riding for my mother. While I was a freshman in college she was diagnosed with Stage 4 Lung Cancer. This came as a total shock to my family and I. My mom never smoked and was totally healthy, but after having a troublesome cough and some pains, she went in to get checked out. The doctors came back saying they found thousands of tumors in her lungs and she had, at best, a couple weeks - at worst, a couple days. She didn't start any treatment, the doctors said there wasn't a point and she didn't want to. "All we could do," they said, "was make her comfortable and enjoy what time we had left."

But my mom is a fighter, and she pulled through. She went from what we thought was her deathbed in the ICU to a wheelchair, and soon enough the wheelchair was gone too. I'll never know exactly what happened, I still wonder how she managed to survive that long, it was crazy. The only conclusion I can draw is that she just wasn't ready to go. So for over two years I watched my mom put up the toughest fight I've ever seen. Sometimes I would almost forget she had cancer, the way she carried herself with such strength and dignity. She never let it stop her from living her life, and being there for her family. Her strength inspired me to take on this challenge. I wanted to show her she wasn't alone in her fight. When I told her that I was riding my bike to Alaska to fight cancer, she cried and told me she would be so proud to meet me in Anchorage.

Unfortunately, she passed away in the May of 2015. She was the strongest person I knew, and I know she would be so proud to see me complete this journey, and to know that I did it for her.

I also had a friend, Timothy Kyler, he was a friend from my childhood. After being diagnosed with a brain tumor in elementary school, he fought his cancer for 5 years. There was never a day he wasn't in high spirits, he always had the best attitude. Whenever I would go visit him, he would never be down. It is only now looking back that I realize what strength he had, that he was battling a horrible disease and yet never let it break him. He was honestly one of the best people I ever knew, and there is not a day that goes by I don't think of him. He passed away in 2007. He inspired me to try and be the best person I can be, everyday, no matter what. And now I have a chance to make an impact in the fight against cancer, so I ride for him.

The worst thing about losing someone to cancer and moving forward is feeling useless. It's so important to find a sense of purpose, or else you feel like you can't do anything. With Texas 4000, I felt like I actually had joined the fight and was doing something about it. It gave me something, a lot of hope and other people to talk to and share my story. I genuinely appreciate all my friends and the people on this team, and what they've done for me so far.

I had plans with my mom to meet her in Anchorage, having her absent when riding in was tough. But I had support from the team and my family being there. I knew it was something she wanted me to do.

Ria

My dad had cancer. He had gastric cancer, and we found out the summer before my senior year of high school. He passed away the summer afterwards, which was right before I came to UT.

How old were you?

I was 17, and then actually the year after that my aunt got Non-Hodgkins Lymphoma but she's in remission now, so she's good.

How many siblings do you have?

One. Just a sister. Four years older.

What was that process like for you guys. Was she in college at the time?

She was doing her fifth year at Tech. She wasn't around when that whole thing was happening.

And what was that process like?

My aunt and my grandparents, who live in the town next to us, were the ones mainly taking care of my dad. My mom and dad were not financially very well off, we didn't have insurance. My mom went back to Korea that February after he got diagnosed because she had her own health problems. Korea is cheaper, it was more comfortable for her and she went back, it was fine but my dad's family was not happy about it. They never really liked my mom, she's kind of my step-mom. I'm still close with her though. My sister was gone so it was pretty much just my aunt and I taking care of my dad.

And then after he passed away, did you have your mom here?

No, flights are expensive and since my dad's family was not going to pay for her to come back, and since I was in high school and had no money, she stayed in Korea.

After he passed, what was your coping process like?

My cousins, my uncle and my sister came into town the week after he passed for his funeral. Right after he passed, things just got busy. Everyone came and we were all focussed on having quality time together, we went out to eat a lot. After that, all my college stuff was happening: I had to go to orientation and Camp Texas. I started my freshman year and joined a spirit group and I just tried to distract myself. I was like, "I don't really have time to grieve." My freshman year I learned about Texas 4000, and basically from then on I put all my energy towards that. I left my spirit group and focussed on academics and T4K and that's how I dealt

with it. Now after T4K, I definitely use a lot of distraction still, like right now I'm seeing a therapist every week and it's been helpful- to talk about grieving. I know it's going to be a life long process, but I try to do it in steps.

Did you learn anything about your father after he passed?

Yeah there was some crazy family drama. My whole life, I thought my dad had gone to UT and had gotten his UT in Electrical Engineering. I knew my uncle and my cousin went here too, but I remember my aunt's ex-husband, who is my cousin's dad, met up with my sister and I one time and was like, "hey, here are some things I think you should know about your family. Your dad actually dropped out of UT to work and support your uncle who was getting his degree which is why your uncle is a millionaire and why your dad is... so-so."

That kind of really bugged me, not that he did that, but after my dad had passed and everything, my sister and I got almost zero support from our family. Ever since freshman year, I've been paying for everything myself and I have been working and things like that. They'll give me money for Christmas, but I never saw a cent of the funeral money. When we asked initially for them to help us, they said, "Oh, you should get a bank loan or something." Things like that really rubbed me the wrong way. I didn't really talk to anyone about my dad specifically.

Did you do anything specifically, honor him or carry him forward? Was Texas 4000 kind of that outlet?

I think Texas 4000 was mainly that outlet. Whenever he was diagnosed and going through everything, I was in my senior year of high school. My mind was still very much, “Oh my gosh, I have to make all my moments count my last year with my friends.” I regret not taking enough time to be with him, I would go out with my friends all the time. Either I didn’t realize what was actually happening, or I just didn’t want to realize that. By the time he entered hospice, there was truly no more time. T4K helped me with that, it made me definitely spend a lot of time thinking about him while doing something specifically for him.

In regards to cancer, do you feel a connection to other people who have lost someone?

Definitely. With T4K, when you’re doing the whole thing it’s so easy for people to talk to you about it. You know what they are going through or have gone through and it makes it easy to talk about things. I made a new friend this past year who I didn’t even know, her dad had cancer too and had passed away. One time in the car, we were just talking things, and then it came up and it was very natural. It was nice because I feel that sometimes with people that don’t know what you’ve gone through, it’s very difficult to just talk about it. Either they feel uncomfortable or they don’t want to say the wrong thing. They’re very cautious versus people who have been through it know what to say. It’s fine, but not fine... I don’t know. My friend and I were talking about our experiences with that, and she said, “Oh yeah the whole ‘I’m sorry’ after you let them know.” Are you like sorry because it’s uncomfortable for you or are you really sorry?

Does that bug you, when people say those things?

Me, personally not so much because I get it. It's definitely uncomfortable. You don't know some of things people are going through or how to react. To me, it's fine. It's just always a little awkward because I don't want them to feel awkward or uncomfortable especially when you're meeting someone for the first time and they ask, "What does your dad do?" and you're like, "actually..." It's weird, I was talking to my counselor about this. She was saying how it's ok to give yourself time to think about it and take the time to cry, because my biggest thing is I just would never give myself enough time specifically to actually sit down and think about my dad and everything that had happened. Even with T4K, it was different. That whole thing was its own thing but it helped me with my own process. It's going to be my whole life.

Coping is definitely very different. Sometimes there are moments now, even when I'm talking to you right now that I feel fine about it. And then there are other days where someone will just mention something and I'll start immediately crying and wonder what's going on. Some days are easier than others and some people are just more comfortable to talk with and easier to be vulnerable with.

Have you and your sister had a conversation about it?

No. My family is just very... we don't talk about feelings. If we talk about how we're doing, it's most surface level. I'm doing great or I'm healthy. My sister and I tell each other everything, but we're not very affectionate. We never hug or tell each other, "I love you" often,

but I tell her every little thing that goes on in my life. The same kind of thing that goes on with our emotions, we'll mention some things but never dive deeper. For me, a part of me doesn't think she knows how it works because I was there. I had to be there every day and go through that and see him get sick and see his body change. Everything changed. And then I saw him pass away. Even though she didn't have to see all that, she never got any time with him. I never can tell which of us was better off, but we never talk about it.

Is that something you want to do?

I think eventually, but I still need more time on my own to process it. I think for her, it is going to be very uncomfortable to talk about. She's not a very open person with her feelings. It's going to take a lot of work on my end to get her to tell me honestly how she's doing and not just blow it off or change the subject.

Is there anybody you especially connected with on the ride? Random or teammate?

There was this guy from SenseCorp named Donny and we maybe talked for 20 minutes, but it was kindred, like I was talking about with my friend. We just knew what each other was feeling and even talking, we were saying the exact same things. He had lost his brother to cancer, and his brother sounded a lot like my dad. They had trouble with alcohol and addiction. Even though my dad didn't get that far, he was an alcoholic in his life. Stuff like that. We bonded. That was the person I remember most, the one I remember relating to so much. No one on my route

lost their dad, but on Rockies there were people who had. That was a little... not difficult but I wish I had had one of them on my route so we could talk about it. Talking about my dad on the ride, I can tell them about it but they don't really... know. It's hard to say what I'm feeling and have them not understand.

Is there anything you carry on your person that is related to your dad?

Not necessarily physical, but I have physical things from him like his jackets. I wear his shirt all the time, it's a really big comfy t-shirt. I'll wear those and it makes me think of him, but then more so than that, it's just going through life certain things will always remind me of him. Any time there's a pretty sky because he would always go out of his way to take sky pictures. Cigarettes remind me of him and the color yellow. That snack, Corn-Nuts. Every time I see it because you don't see it very often. But every time I see Corn-Nuts they remind me of him because he would eat them all the time. I don't carry anything *on* me, but I have those things internally I keep that make me think more about him.

Arin

I hadn't really known anyone that had cancer until three summers ago. It kind of happened all at once and my grandma had been acting kinda weird. She sold her house and we all thought it was too soon. She was kind of aggressive but I could tell that she was aggressive because she was in a lot of pain, I just didn't know why. Whenever she would get angry with us, I wasn't scared. I don't know, I could just tell there was something going on with her when she would get angry like that. And then, there was one summer where it all kinda came at once. I found out that my aunt Cathy and then my grandmother Sonya Hartley, I called her my Tattie, they had cancer.

With my grandmother, it all happened very quickly. She got cancer late in the Summer in July or August and then a few months later she passed away. With my aunt, we found out she had cancer early in the summer, end of May or the beginning of June, and she's still alive which is great. With my grandmother, I'm not exactly sure what type of cancer she had. I think it was in her lungs and then it kinda went throughout her whole body. She had been a smoker almost her whole life since her first marriage at 18 or 20 or something but then towards the end, she actually quit smoking. With my aunt, we first found it in her hip, in her bone and in her lungs and in her brain. She started intense treatment immediately and lost all her hair and it was really hard on my mom and all her sisters but especially my mom because they were twins so I think they have this connection that I can't even understand as a sister.

Having a twin is, like, you came out together into this world and my mom always thought that they came into this world together and they would leave this world together. My mom's

mom was an alcoholic and couldn't ever really function. They would come home from school in Second Grade and find her on the floor so my mom raised them both and her other sisters were much older. My mom would take care of Cathy and cook for them and do all their laundry and help pay the bills if she could. Her dad was kinda verbally abusive and was never around so I think my mom felt like they had this intense connection too because she kinda helped raise Cathy.

Cathy was almost always a little weak and my mom was always the more confident one. Now, the outlook isn't great. I'm kinda surprised she's still alive but it's gotten to a point where the treatment is killing her more than the cancer is so she's kind of in this place of "Do I keep doing treatment? Do I stop treatment and try to live a better life?" She's got a couple little kids and that makes me sad.

Where were you when you found out about her passing?

When I found out about her passing I think I would come back to Austin but we had just seen her one or two days before because we knew it was the end, we knew it was super close and it happened in the middle of the week. I think we saw her on a Wednesday, or something, and she died on Thursday night or Friday morning. So we knew that it was gonna be really soon. Everyone says this and I don't really believe in spirits, but I think that she was kinda trying to hold on until we saw her. And I remember the last time I saw her she couldn't talk and she couldn't even really respond with any kind of physical movements or body language. Her best friend emailed us this letter to read to her and her best friend at the time had MS so it was like a

translator typing this email for her and it was beautiful. They'd been friends their whole lives and they talked on the phone every day.

Everyone was crying and I'm normally a very emotional person but, for some reason, I was just able to click into it and read the entire letter without crying to her. I was sitting over her and I could see her eyebrows move up in the middle like if you were about to cry and I could see her mouth twitch a little bit and I knew that she could hear me even though she was unresponsive. Then I said my last words to her as we were leaving and gave her a big kiss, or a few probably, and we all said goodbye and it was like a late night-early morning thing. When they found out she died I think she was in their living room on her bed and then my grandfather came out and saw her and probably cried for a long time and knew that she'd passed and called some people to come get her a couple days later.

I was at home. I don't really remember it too much but my dad was really upset for a long time which was also weird 'cause he'd never really been emotional. I think I'd seen him cry once in my whole life before that and now he still cries talking about her or if we're talking about her.

So especially with the struggle your family's going through with your mom's sister, what would you say the coping process has been like kind of cohesively among you guys but then also specifically for you?

For me, I am just trying to be strong for my mom. I think all of us around her are kind of that way. Me and Wendy and my dad cause she's really struggling. She was her best friend and her sister and soul mate and--very unique type of pain. I'm sure I will be in a lot of pain when she

does pass away but right now I feel like I'm able to just shove that aside to be there for my mom in kind of a survival-type way.

So we're all kind of responding like that. And then all the sisters together and the way that they cope, I think they have something special that we can't relate to. They talk about it differently than we talk about it with her. My dad has been really good about being there for her because my mom comes home from work almost every single day upset and he's been so patient. I don't know if he'd even have that if his mom hadn't passed away.

I was just about to ask do you think that it has something to do with that?

Yeah, I definitely think so. In a way I think he doesn't really know what to say to her a lot of times when they're talking about it. I can tell he's just very quiet but he listens really well. It's very different--a grandmother passing away--they've had a full life and beautiful life and I got to meet her. All her other grandchildren got to meet her. I have fond memories of her as an adult but Cathy has two little kids and no grandchildren yet. She's super young so I think my dad doesn't really know what to say in that realm but what he did get from his mother passing away from cancer was he just knows the most important thing is to just physically be there with the person and just say, "Hey, I know you're in pain but I'm here" and that's like the most you can really give anyone. Just say, "Hey, I'm here and I'm listening and I can give you a hug. I don't know what you're going through but I'm with you" and I think he gets that, which he probably wouldn't have before.

And he does that for your mom?

Yeah. That's how I think all of us are kind of responding for her specifically.

What were some of the weirdest aspects of the first several months to a year after your grandmother's passing?

The first few months it was a shock cause I think it was right before Christmas and she always did Christmas really big. She has this huge Christmas tree in her house every year. She always had the same decorations. They were Mardi Gras colors. She would set up this little train track around her house. She was super into it. She always got us tons of presents like this big Santa bag full of presents. She was the Queen of that. Christmas came and all of us were just kinda quiet about it and I don't think we even got together for Christmas. This other big family event we do every year called The Pig Roast, we go out camping at one of our family friend's ranches. We do a pig roast and very Texas things, shoot guns, go mudding, and stuff like that. We didn't have that either.

We didn't really see each other a whole lot for the few months after 'cause I think everyone was in shock but I cried a whole lot because I was just lost. She was so much to me. For a grandmother, she was a mentor to me. Like, "Who do I ask about boys now?" or "Who do I complain to about my dad?" I wanted to tell her about Texas 4000 and I couldn't. The last time that I talked to her about T4K it was like, "Hey, I think I'm doing this thing. I'm real excited about it." She thought I was absolutely crazy and I don't think I ever got to tell her that I made it in. I certainly didn't get to tell her my route or that I made Ride Director or that I'm making these friends or that I finished my sentry or the big benchmarks.

Even a year after, I still cry about it a lot. My cousin Shawn, surprisingly, who's very emotional about it but really quiet about the whole thing, apparently a couple months ago he called my cousin Alex (they're brother and sister) and he was crying and he was like, "I'm just so upset about Tattie" and at that point it had been like 2 years, three years. And she was like, "Oh, I'm here. Talk to me" and he was like, "Never mind, I can't" and hung up. So, he's still very much in shock. I feel like I've come to a good place with it especially after the ride and after hearing everyone else's stories and talking about it a lot. You feel like their memory gets spread around which is really nice. And you see when talking to other people about their grandmothers or moms, or whatever, and you can share that bond and you see it helps them a little bit, it helps you a little bit. So, I think I'm lucky to have had that when my sister and my dad haven't had that.

Rusty

All right. Yeah, man, just start off with your story. Tell me about your tie.

For sure. Beginning of my junior year of high school, kind of end of the summer going into that year, my dad went into the hospital a couple times. Didn't know what was going on. I think it was the day after my 18th birthday, my parents went to MD Anderson. He was diagnosed with pancreatic cancer. Junior year, sorry. Not senior year. So 17th birthday. 95% of the people who get pancreatic cancer get a pretty common variety. There's three varieties, whatever you want to call it, that make up the 5%. He had one of the rare forms. For the first 12 to 14 months, it was kind of, "Let's try this. Let's try this." Whatever worked, whatever was doing good things, they continued.

Around Thanksgiving of my senior year, it metastasized and got really bad, really quick. He had to start taking methadone, which is the pain killer that heroin addicts take when they're going through withdrawals. That messed with him, mentally. He spent time in the hospital, in and out of the hospital the last couple months. This whole time ... I'm the youngest of three and going into my junior year. My brother's two year's older. He had just left for University of Virginia. I was the only kid at home. My mom worked. My dad was a stay at home dad.

It was bizarre, in the sense that I was trying to learn how to be the only child and then also, I ended up taking care of my dad towards the end, when my mom was at work and I was at home after school. There was a lot of juggling and chaos that I didn't really acknowledge at the time because you bear down and try and keep on keeping on. It went bad really quickly those last

two months. He ended up going into hospice on the morning of January 18th. He passed away, like 2 a.m., on the 20th. It was really rapid.

How old were you?

I was 18. What I'm grateful for, but also sad about, is I was there but my sister and her husband ... She's five years older than me and married. They wouldn't answer their phone. He started going downhill like 11:12 Saturday night. They weren't there. My brother was flying back from Virginia Sunday morning. We never thought it was going to be that quick. I was able to get the room to myself and say a farewell, have intimate time with him. There's a lot of cool stories around those two days that have impacted me dramatically since then. My brother and sister, I don't think, got as much closure as I did. I've never really talked to them about that. It's still raw for them, I think, a little bit more than me.

You said you haven't talked about it as much with them. What have your conversations with them about it sounded like?

My brother and I went to Omaha, Nebraska for the college world series the summer after my freshman year because UVA and UT were both in it. We thought they were going to be in the championship together. The back story is my brother and dad got to go the last year that the tournament was at the old stadium and so there was sentimental factors, I think, affecting my brother. At one point, we were driving and I brought up my dad. One sentence in, nothing really that deep, my brother's like, "I don't want to talk about it." He went to UVA and joined a

fraternity. That's right when my ... Went to UVA, my dad was diagnosed, so his whole college career was impacted behind the scenes by my dad having cancer, then by my dad passing away.

I was able to come to UT, not necessarily with a clean slate, but didn't have my dad having cancer, my dad passing away be the thing that my friends knew about and all of that stuff. I don't know if that impacted it. I think I have probably more intimate relationships with people here through BYX and Young Life and Texas 4000 that I don't think my brother has developed. My sister was, I wouldn't say uninvolved, but wasn't around as much as I was, obviously, through the process. She had her husband, who I'm sure she confides in and was vulnerable with, but I haven't gotten to have those conversations with her. She got married June of 2012, so in the middle of my dad's treatment. She has very much confided in my brother-in-law.

My mom and I's relationship has taken off. It's super awesome. She one of the best people ever. She grew up in the church and has a faith and, I think, has been comforted a lot by that. My brother and sister haven't really developed a faith. I have, since my dad passed away. Through his treatment was a big story. It's interlocked with me pursuing my faith and my mom also rekindling hers. I think that's also brought intimacy into our relationship and opened the door for conversations about my dad and cancer and all the sorts of stuff like that.

Were you especially faithful before? Was your family?

My family was not at all. They're super hands off. I went to a couple random youth groups in high school and my mom went to church every Sunday, growing up. We went when we were little, then we got super involved in sports. My dad was a coach, so we stopped going to

church. My mom kept going. We'd stay home with my dad. They didn't push us one way or the other. If we went to youth group, we went to youth group, whatever. The summer before my junior year of high school, so right before he was diagnosed, I started going to a youth group in Westlake. We would play ultimate frisbee at Zilker and hang out. The youth leader there invited me into the group. It didn't seem like religion. It didn't seem like anything. He just wanted to get to know me, and care for me, and love me. That was probably the most attractive thing that I've ever seen in religion. It's cool, looking back and seeing the timing of all that worked together. How I got involved with that group and then my dad was diagnosed. I gained friends through that and relationships that supported me and helped me when he passed away. Then I came to college, and I wouldn't really say that I understood the gospel until the summer before my freshman year of college. Ended up coming here. Crazy situation got me involved with BYX. I had ants in my dorm room. People had to come kill them two days before school started. My roommate was going to get breakfast with one of our older friends, who's in BYX.

I had to leave and I went to breakfast with them. I didn't know what I was going to get involved with. Our friend said, "Hey, there's a BYX Rush event at Zilker today," which is what I had started doing in high school when I got involved in the church. So I went and got involved. Got involved with Young Life and found those same sort of relationships that I'd established in high school. There's a couple guys on staff who filled the role of my youth leader from high school that cared for me. There's not really an ulterior motive or desire. They just want to love me well. That's had a hugely profound effect on me and the way that I view God.

What specifics things could you say that this presence in your life now has helped with?

Like the grief and coping process. Do you have specific instances?

I think, and this is a tough thing to say, and I think hearing it from the other side, I could imagine being like, "Whoa, that's a little weird," but because of my faith, I believe that things can be redeemed. I've been forgiven of something incredible and so I can forgive. Those last two days that my dad was in hospice, there were two big things that I'm struck by that I tell people about it. My dad and mom had a really bad relationship. He had a really tough childhood. We don't think he really understood unconditional love. The older we got and the more independent we got, the less worth he felt, since he was a stay at home dad. There was a lot of internal strife within the family. He did a lot of things he shouldn't have done. Every family has that sort of thing.

That was a huge impact in why I initially started going to church. I understood how broken he was. I saw a lot of him in me and was, honestly, terrified that I would become him. That night that I got the room to myself to talk to my dad, I, at that point, didn't really believe in God. I could not articulate the gospel, but just sat there and forgave him of everything. Like I said, I'm super grateful for that and wish my brother and sister had had that sort of thing. Looking back on that moment, I don't hold on to the bad that my dad did. I cherish the time I had with him and wish more than anything that he was still here. That freedom that I gained through forgiving him of all of the wrongs that he committed, I don't think would have come around if I hadn't understood that I am just as broken.

The other part of that is the redemption that I saw Thursday night into Friday morning, right before he went into hospice. He apparently kept telling my mom, "I love you. I love you. I love you." My mom told me this a couple years later. That was probably the most intimate 12 hours of his entire life. He had to understand that this was the end. He probably wasn't going to make it out. He wasn't going to make it out. He could have said anything. He could have done anything. He could have been pissed off at his situation, but he kept telling my mom, "I love you." My mom told me that that was the first time that he had told her he loved her since she told him she was pregnant with me. At that point, it was probably 19 years that they'd been married and my mom had been waken up every morning, caring for us, going to work, providing. I saw so much redemption in that. We see people a lot in our lives. We don't really believe that they can change. In the end, my dad did. I think that impacts a ton of relationships that I have, with a) forgiving, like I talked about, and b) redemption is so sweet and free. Those are the two big things that I've found from that moment. Through that, cherishing the time that I have with people is huge. You don't really understand how valuable people are in your life until you lose them. As much as I with my dad was still around, that's an incredible lesson that I learned. I still have my mom, and my brother, and my sister, and incredible friends, and aunts, and uncles. I think part of that is me growing older and maturing, but another part of it is me understanding that they can be taken away in a moment's notice. You become more present with them. Put away your phone. Try and care for them and love them better, because you don't know how much time you have.

What would you say was the strangest thing about the afterwards? These years that have happened afterwards? What has been the strangest part of this overarching process?

I would say that there are moments, even now, that are still raw. I probably cried every day for weeks after he passed away and started slowly stopping. He gave incredible hugs. That's probably the strangest thing. My dad gave incredible hugs. Like I said, he wasn't the best father on the planet, but who is? That's what I loved most, is coming home from a tough day at school or being stressed out, I'd get a hug from my dad. That was the thing that I missed the most, was his hugs. Over the last few years, whenever I feel worn out or vulnerable or in need of a hug, that's when I miss him the most. I've got a couple friends that give really good hugs that remind me of my dad. It's the little things that remind you that are very unique to the relationship that I had.

There's probably random, other little things that other people are reminded by. Smith, one of my best friends from Texas 4000, every time she sees a cardinal, she thinks of her dad. There's little things. My dad loved baseball and was the equipment manager for UT, so when I get to go watch a baseball game, that's a cool way of honoring his memory and his love of the sport. It's those little things, remembering what he loved doing and then when I get to do it, it's like I'm sharing it with him again because it was his passion, his love.

Sirena

Growing up the only memories I really had with my dad were just sitting in his big, rusty red truck and listening to 80's music with him or just doing like, always trying to get in the way with my brothers and trying to be the girl that was with a bunch of dudes. I don't know. I think once I started high school and once I started thinking about college and thinking about how I needed to be this ... this specific person that looked good on paper. This person that made my parents proud. This person that was a role model not just for me and my siblings but for other people, just being a Hispanic woman who came from immigrant parents. I feel like I strive to be this ideal image, and I feel like that image was shattered when my dad was diagnosed with Stage 4 Adrenal Cortex Carcinoma. It just came out of the blue.

I think, like 3 months ago we were in Mexico, in beaches and were just trying to have a family vacation. I feel like I didn't get to do that a lot with my dad, because he spent so much time trying to be a father, trying to be a provider, trying to make sure that we always had what we needed. I think that he wasn't always there, around for me to be able to do that, or around for my siblings to do that. When I think about my dad, you know, I think most of the time that I was around him he was sick. It was just out of the blue. My mom was giving him a massage one day and there's just this giant lump on his kidney. You could just feel it and it was the size of like, an orange. I remember I came over and I touched it, and in my head, you know you would think, wow the mind is such a powerful thing that you would automatically, you want to dismiss it and want to shut yourself off to that pain.

I thought, "Wow, no. This is like a food baby." I don't know. I was trying to make light of the situation that deep-down, I knew was not a good thing. I think that, that's something that we all do when we're faced with the possibility of experiencing something traumatic that you flinch and you run, your body and your mind wants to preserve this reality that you carefully constructed through all these different ways. After that things changed very quickly, so after that they told my dad he only had 6 months to live, so he first got this surgery done that just removed everything it's called, "debulking," and so they removed his kidney, part of his liver and he was just laying there with a bunch of stitches all the way from the bottom of his stomach all the way to the top, and I just remember being scared.

I didn't want to be around him sometimes, because I didn't know what to say. What do you tell someone that is trying to cope with the fact that they're dying? I think as a society we never think about dying as a normal part of life. We don't ever think about that when you're 40, when you're 30, when you're 50. I mean, we think we've done so much in modern medicine to prolong life that we never think about the fact that we are dying. We're dying every day, and I just remember being there with my mom and my little brother and we would just like clean his stitches and his wounds. They would get infected because he was so sick and he was just laying there and putting like, a bandana on his head, because he would get fevers and he's just always sick and, he during this moment he tried to be my dad as much as possible.

He tried to ask me how my grades were doing, how this was going, and you know, I think I put both situations in such a different sphere I put all of that in one aspect of my life and I hid it from everyone and anyone. I didn't tell anyone he was sick. I didn't tell my school, I didn't tell

my friends, maybe because I was scared that if I said it, it would be real? Maybe it was because if I felt empathy and if I felt that pain that I was running from I wouldn't know how to deal with it. I think I spent those 6 months running away from that. After that he was put in like chemotherapy, and they were giving him pills but, I mean, his cancer, none of the doctors who saw him have ever seen it before.

Now, as a UT student I'm doing a research project on his cancer and it's frustrating knowing that, like, now that I'm doing it four years later, there's still nothing. I'm writing a paper and it's hard for me to even get to 8 pages on something. It sucked. It's like that he'd be taking this medicine and I just, he was just sick and I remember one day I came in from school and my mom was begging me to come in there and try to comfort him. I came in with a plate of food and I gave it to him and he started eating it and then he just pushed it away and it landed on me and he was just throwing up. I think, I know that was really hard because he just kept apologizing to me after he did that, and he almost ... I think that, at that moment I knew that he felt ashamed that he was sick, that he was not going to be able to be there for us.

In the small moments where he was like, saying sorry, he was actually saying sorry for a lot of things that until now, as an adult, I can kind of finally understand. After that I feel like we kind of, those next few months, I think they went by so slow and painful. He was always just sitting there on the couch. Whenever he would try and go for walks with my little brother or do something it was hard for him to do anything. I don't know. I think during that time our family was divided, I think, like nobody was comforting each other. I think everybody was trying to heal their own wounds or run away from them because you don't really know how to react to

something like that. I always wish I could have been able to have a real conversation with my dad about how he felt, but I don't even know if he knew how he felt. I think he resorted to faith and to religion and to being there and fully present as much as possible, but I didn't resort to that. My brothers didn't.

I think everybody copes in a different way. Out of the blue he just started getting more and more sick so he was just put on dialysis. His body was shutting down. He had tubes down his body. He couldn't eat. His body was literally withering away. I mean he was skinny when he was in the hospital. There were parts of him that were black and purple and it's crazy that he was literally withering away in the most painful way. No amount of morphine can make a difference or pain killers. I just remember him being unconscious but his hand would squeeze my hand because he was in so much pain and he couldn't say anything. It was really hard. I mean I can always hold onto the fact that he wanted me to be a better person. He wanted me to chase my dreams. He wanted me to be the best person possible and to fully live life, and I think that's what I am trying to do.

I'm trying to live my life and I think that when someone dies you die too, a little bit. Like a part of you dies. I think you put your life on hold in so many aspects. Like you start shielding yourself, you start guarding yourself, you start putting other things before how you feel because you want to be put together. That's what I did for my little brother. I was the one that was kind of walking him into the hospital room, or the one trying to explain things to him. I was the one that told him that my dad died. I was the one that told him that day in the morning when he walked into the room that he passed away.

I think from then on, silently, I don't even know how we did this, because we didn't talk about it. I think we all agreed to not, to move on. To move on in the sense that we just put our pain aside and just like try to be there for my little brother. I don't think we ever learned how to grieve together. I don't think we ever learned how to do that. I think we all, individually, went through our own journey of having to figure that out, because my experiences losing my dad is different than my brothers, because they had a different relationship. My mother lost someone that she's known for so many years of her life. Someone that provided not only emotional support but financial support, so I think it was very difficult.

What are the things that you've done, the things that you've found about life that have helped you through this process? This process of grief and coping?

I think coming to UT, coming into a different setting where I know and knew that that happened helped me find myself. When I realized what I needed to take care of myself it helped me realize what I needed to do to grieve and to cope. I think ... I didn't tell anyone, I think the first person I ever told was my roommate. I kind of went into the story and explained to her how it kind of affected me and how it still is. It's a never-ending thing, but it was removing myself from my family where I was able to finally have an ability to move on, I think. I don't think you ever move on. I think it comes in waves. I think pain comes in waves. Like, sometimes it hurts a lot and sometimes it doesn't.

Sometimes little things remind you of something, and the other individuals who lost their parents to cancer, and that helped. Because no matter how I dealt with it, someone else was dealing with it, too. Doing T4K helped me move on in a sense that it let me just let out so much

ugly in me. So much pain, whether it was related to my dad or other things. It helped me sometimes be selfish, sometimes be angry or just live and just see things. It helped me realize that there's much more to life than what I just have already seen. Because I think when you see something so ugly you wonder is it all worth it? I mean what ... I went through a lot of issues with, like, dealing with my depression and just my own body image issues and it was really hard, but I think just like experiencing life helped me, and that helped me be there for my family. I think that helped them with their grief, knowing that I was dealing with mine in a more positive way. Because I think at the very beginning, I definitely wasn't dealing with it in a positive way.

I think I was just this Type A human being. Very anxious, just high-achieving. Just ignoring everything and I think when you have an open wound, when something's so traumatic, it's like an infection and it just gets worse and worse and it builds up and you have to go through this painful process of dealing with it. I think coming to UT was that for me. I think being involved in these other organizations helped me and just finding people to talk to. I think the, not with grieving, like yeah, talking to people about it, but finding those people that remind you that there is other things to my dad's story. Like, and I tell people I never ... I never had the chance to be like, "My dad used to do this for me," or, "My dad, we listened to this song," or "My dad his ringtone was this," or, "My dad loved to watch this with me." I never had the experience to do that with a lot of people because it focused on the ugly, because that's all you want to do. Your mind is primed to remember these ugly, important facts and events and I think other people focused on that.

But meeting other people that saw more than that helped me realize that there was more to my dad than him dying from cancer. That there's more time him than rounds of chemotherapy than just laying there, not being able to move, throwing up. There's more to that, and I think that's what helped me was realizing that I can still see him every day. I think, like feeling him. I think when you learn to grieve and you start to feel that person that you lost. You, you're not, no longer blinded by pain but you can feel that person in another individual, in a song, in a smell. Someone told me that they felt their dad in a dog recently. It might sound so hilarious to someone else but to me I think that's so true. You sometimes feel this individual that you've lost through other people and I think that's an important thing that has helped me. Knowing that I can feel him sometimes if I let my heart open up to ... oh my god, I sound so corny.

Don't worry.

But that's just how I've learned to kind of deal with it, and I think time, I know that sounds so cliché that time heals all wounds, but I don't think it's time. It's just what you do with that time and how you live in that time that you experience life. I don't know. I, it's ... Sometimes I forget that it's been like 4 or 5 years, because sometimes it feels like it was just yesterday. Sometimes it feels like it might have been longer ago. I don't think I ever stopped being upset. I don't think, I know there's definitely some days where I cry more and some days where I'm happier and I remember him through a very positive thing.

I don't know. It's a hard journey and I think it's a never-ending one. I think you learn to lose to experience loss, and it's a learning experience. I think some people are more equipped to deal with it. I think not being able to have a longer, like more closure with my dad made it such a

difficult experience because there was 6 months and he was gone. I think, I always hear how people say if they were to have a diagnosis of terminally ill cancer or disease, that they would want to live life to the fullest and be there for their family, but sometimes that's not possible. Sometimes the person is legitimately that sick that they lose part of themselves to that ... But just holding onto the positive things in the end has helped, you know?

Cecilia

Starting from the beginning, in January of 2009, my sister was diagnosed with acute myeloid leukemia. It was a huge shock, it was weird though because she'd been sick for about 2 months and she kept going to the doctors and no one really did blood work. They thought she had lockjaw and all these different problems. I remember one day right, they took her to Texas Children's on the 10th of January. I was getting ready for carpool and I googled symptoms of cancer. I was like fourteen years old, but I was just like, "what is this?" I was always very interested in medicine.

How old was your sister?

She was 15. She ended up being diagnosed with leukemia, so we called Texas Children's our home for the next nine months. I always tell people when I tell my story that the grieving process starts on the diagnosis, and I think that's the one difference between a loss from cancer and a motor vehicle accident where, one day, they're healthy and then gone the next. A part of your brain goes survival mode right when the diagnosis occurs because you have to be prepared for it. When you think of cancer, a lot of time the outcome is death. I think it all hit us hard, and it was almost like a part of our family died. There was such a shock. I remember being in the corner of the ninth floor of the hospital and my dad was hysterically crying and my mom, who actually has been working on that floor as a nurse now, was all together because someone had to hold the ship for my sister. When we finally got ourselves back, we went with my sister to her

room, and knew we were gonna do this. There was no other option, and I think when people say “Oh, I don’t know how you and your family did that,” I say anyone can do it when you’re put in that situation, the human body and the human mind and family are so strong and can withstand so much. It made our family closer, I mean we were with each other 24/7. I was homeschooled thankfully. I think it allowed for a little more flexibility because I was able to be downtown with my family. I spent a long time with my sister there.

She went through three rounds of chemotherapy, and she did incredibly well. She was the star patient. My dad had no control except for keeping everything as clean as possible. He would freak out when anything was dirty. We all kind of had our little part to play. We felt like they were our little duties. My dad was the clean freak, my mom was always being educated on the treatments and I just had to be there and play with my sister. There were special times where I really needed to be there for her, like when she shaved her head. That was a huge moment for her because we all knew it was coming. It was really emotional, but I thought she was the most beautiful bald person in the world. The experience was memorable.

I don’t think I can say “Oh, it was the worst.” I mean yes those nine months were the hardest my family ever has ever had to go through, but I have memories that are still with me that I think about all the time. At one in the morning on the nurse’s station my sister and I made posters. We would have movie marathons, we celebrated the good news of good tests that came back and we cried together. And then she relapsed.

She had a bone marrow transplant in April that actually came from from my mom, which is actually kind of rare because usually it’s a sibling. You have ten markers and 5 come from the mom and 5 come from the dad, and you need 8 so usually the sibling has more, but weirdly

enough my mom had 9 markers so it means my mom and my dad probably had some weird connection. It was crazy. The doctors said that that usually didn't happen. They did the transplant, and you have a hundred days after the operation they count. If you pass a hundred days, the operation is a success. Unfortunately at day 97 she relapsed.

That was a rollercoaster in August. I can't imagine what my sister thought. Our family knew what it meant. You already know what's going to happen. If you go back to January, it's a little different because we didn't even know what was going on, but in August we knew exactly what was going to happen. We were going to have to go back to the hospital and back to chemotherapy. She was already kind of weak. Her body wasn't where it was in January, and so she went back to the floor and got a little more sick. She had a fluid overload in her lungs and ended up in the Pediatric Intensive Care Unit in October. I didn't even realize how bad it was, I just assumed this was like every other time she got a little more sick.

I had actually joined public school September of that year. It was so lonely a lot of the times at home, I needed to do something to at least get my mind off of it because it was my whole life at this point. I remember going to the PICU with my dad and saying, "Well I have to be back home by seven because I have this and this," and my dad looks at me and says, "Ceci... your sister is dying."

I'll never forget that, because I thought she was going to get out of there and she was going to go through treatment and then go home. Sure enough, two weeks after that, she passed away. It all happened so fast, she just progressed every day. We had time with her those last two weeks and my parents talked to her about the fact it was coming to an end. She was worrying about what it would do to us. She was so scared of how much it would affect us. That just shows

her spirit and who she was. She was so selfless, and we were able to have about an hour together, the two of us and we talked about not being able to be each others bridesmaids. That hour was something I will think about for the rest of my life. I have so much gratitude to the nurses who let me have that time because they didn't have to do that for us, and they made sure that I had that time with my sister. My dad lost a brother to leukemia and he wasn't able to say goodbye to him. I know that affects him to this day, and for me I was able to hold my sister's hand when she passed away when we took off her breathing tube.

It was hard that she had to pass away in a hospital, but I think it was as good as they could make it. My parents actually had to make the decision to stop the treatment care because she was intubated which means a tube down your throat is really the only way she could breathe. And they probably could have kept her alive for another two or three weeks but she would have essentially been a vegetable, and I know my sister wouldn't want to live that way. I can't imagine how hard that must have been for my parents to make that decision. We were all able to be there when she passed away, and I'll never forget it. Like I said, it the way I think we all wanted it to be. We were all with her, and she didn't suffer.

I remember the next day actually, it was a Wednesday. I ended up going back to school and I remember my teachers asking, "why are you here?" I couldn't just sit at home and cry, I had to do something. I had some breakdowns that next month. She was my only sister, so it was just me and my parents. They were such an incredible example to me that basically we had no other option but to move on and give back. Yes, it happened but we wanted to do something to help impact the cancer community.

We stayed in touch with the doctors, the nurses and the other families. My mom ended up going back to nursing school. About a year later, she made the decision to go back. She took 2 years to graduate, and her first job was on the same floor that my sister was treated on. I can't think of a more incredible way to put your heart, your grieving heart, into something you're passionate about. I think it just showed me that there's no other option than to live in her memory and to love. To live as she would have, and to do things to make her proud and to remember her. I talk about her all the time. I probably annoy some of my nursing school friends but she was the most person in my life and still is. She still inspires me every day. Being able to come to UT and immediately join Texas 4000 was the most life-saving thing I was able to do. It was such an incredible way to grieve and share her story. I told the new team that they'll be surprised at how much you grieve over the summer for things that happened so long ago, but I found my sister there during those seventy days. We got closer. Some of my best friends who rode with me still talk about my sister as if they knew her because we were able to have those conversations, and it brought her to life again. I am so grateful for Texas 4000. We were able to wake up every morning and have a purpose.

My purpose was to ride for her and for the other kids we met at Texas Children's. Being able to go back once the ride ended and go to nursing school, like my mom. My mom is my hero, she really is. My goal was always going to work on the pediatric oncology floor, but unfortunately, it didn't work out this time. After PICU, I'll have a lot of really valuable things to take to an oncology floor. Maybe it's because I see the way my mom is, and she's such an inspiration to me. You can live a full and happy life after someone you love passes away. She's done it just by putting everything she has into what my sister would have done. What happened

to my sister led to meeting so many new people, and while I wouldn't wish that on anyone, it happened and we are going to embrace those people and that hospital and how the experience changed us. My parents were definitely the ones that kept me going because sometimes friends asked, "how can you be happy?" If my parents can be happy when they lost a child, if they can still smile and wake up every day... then I can too. Millions of people lose family every day, you have no other option than to go on. I think if you dedicate your life to living for that person, and you do so in their name and their spirit, it makes life so much more beautiful and it has. It really has.

Well, would say were some of the strangest parts of coping?

The strangest part about coping was that I honestly grieved more later which was just so bizarre. Every one kind of assumes, I assumed too, that you grieve right when the loss happens. I had just turned fifteen, and you think those next two years would be the hardest, but I would say the hardest were these years in college. I think maybe it's because you grow a little more in college and you realize how important family is. The hardest has been hearing friends say "Oh, I'm gonna go visit my sister" or seeing friends getting married and I think about all the things I would have were my sister be alive. I find myself grieving and getting really upset about it more than I think I did in high school, weirdly enough. That's been the most bizarre thing. As time goes on, you think it gets easier but it only gets harder. You're worried that those memories will fade, and you worry that as time goes on that person will leave your heart. Like I said, I'm so thankful that I had Texas 4000 because it did bring her to life again. It resurfaced those feelings

and emotions that were hard to deal with. I'm happy I cried, and I like crying about my sister because I feel like I have her next to me for the moment.

Do you think that you shared a lot of this strange experience with your parents?

I think my parents were people who grieved on their own. My dad fell into a depression a few years after, and I had no idea. He kind of mentioned that he would wake up every morning crying. I think my dad especially is learning to deal with it a little better now. At the beginning, he didn't have very good coping strategies. He wanted to move away from everything that reminded him of my sister being sick, whereas my mom and I we kept going back to the hospital. We volunteered there every month and worked with this organization called Big Love that brings toys and food to the families of the cancer center. Being there helped us to remember her spirit and the happy times. My dad didn't want to go back. It reminded him of what ultimately killed his daughter. I think that showed me the two different ways that my parents dealt with it. My dad was just so upset and angry and my mom was a little more, "it happened and how are we going to give back?" I think my mom and I dealt with it similarly. My dad had to deal with the shadows alone. A lot of men don't like to be seen crying which I hate. I think men and women both grieve strongly, and need the same support regardless of who they are.

I think there's something really unique about me being another person who has lost a close family member whether it's a mom or dad or a sibling. If you randomly find that out about someone, it's this instant connection. I might not know your whole story, but I know exactly the feelings you have felt in your life. You can get to know someone in a way that feels like you've

known them for five years. You go past the bullshit and immediately get to those feelings. It allows people to have more open conversations than the standard, “Oh, I’m so sorry that happened.” Instead, “Oh, what was your sister like? What was she like as a person?”

McKay

Feel free to tell your story how you want to tell it.

So I usually start talking about this in sort of an odd place. At least I think so. I start with my grandmother who did not pass away from cancer. So my name is McKay. That is my grandmother's maiden name. I was quite intentionally named after her.

So she raised my dad and his three brothers on her own after my grandfather walked out when my dad was eight. And, I take the honor of bearing her name really seriously. Like that matters a lot to me. That the person who is not just genetically responsible for my being here but is realistically the reason that my father succeeded was because he had such an incredible woman sort of as his role model. And for him to take her name, or at least part of it, and then give it to me, that means a lot to me.

And the reason that she had to do that was my grandfather ran off with a younger woman. Right, it's like a complicated situation but that's the short story made short and because of that my father was obviously a lot closer to his mother than to his father. And even though my grandfather was in my life, it was really in a fleeting way. Like we visited a few times. He visited us a few times. Things weren't just like totally ice age frozen out, but it was always sort of stilted to me. 'Cause even when I was real young, I didn't quite understand the whole situation and couldn't wrap my head around you know how everything had happened, much less the why of it.

And I've always, sort of, the more I've understood then, sort of angry with my grandfather. It's always been something that as someone who is sort of emotionally sedate, not

too worked up about anything, it's been one of the things that really touches a darker side of my emotional spectrum in a way that I'm not used to a lot.

And that's been pretty consistent about the way that I felt about my grandfather. Like, I've had conversations with him. I've met him. I've done the family thing with him. But, the idea that he would leave his wife and his children in the lurch just to run off and do his own thing and not be a part of their lives and not invest in them, and by proxy to sort of give up on the idea of me. That if his sons weren't worth his time, then clearly his grandsons aren't worth his time.

That's been something that really, really strikes a nerve for me. And I've always had that sense of resentment inside me. I don't talk about it a lot. I don't bring it up to a lot of people. It just doesn't come up organically with a lot of folks. You know people ask about people's parents, they don't ask about their grandparents as much. And when I do talk about my grandparents, I by and large talk about my grandmother or my maternal family, but I don't bring up my Grampa Frank that much.

So a single digit number of times, I spent time with my grandfather, but only usually for a few hours at a time in my childhood. And then I don't remember the specific years, because I'm just bad at that sort of thing, but in late tweens, early teens, he was diagnosed with prostate cancer. And then about a year later we found out that it had metastasized to his lymph node and then maybe a year later I remember being on our screen porch and I saw the phone ring and on the caller ID it was Kathy Proctor not Frank Proctor my grandfather, so it was the woman he had eventually married after running off. And at that moment, I just sort of knew. It was just like one fourth of my genetic history has sort of shuffled off this mortal coil, right?

In that moment, I felt more a sense of anger tinged regret, than sort of wishing I'd gotten to know him better. There's a part of me that sort of wishes I had known him better for positive reasons, but there's also something bordering on hatred about it that just really in that moment sort of catalyzed. I was aware of that feeling, but knew that it was not the thing that you talk about in the immediate period after someone's passing.

I knew that especially for my dad, it was a really complicated time emotionally, and for my dad's family it's still sort of an odd thing in the way that they handle it and talk and don't talk about it.

So as a teen, I sort of held that inside me and was always angry about it whenever I thought about it. And the way that cancer played into it for me, sort of feels different from what it means to most people, right? We talk about this disease as something that ends the lives of people that we love. Right. That's the tragedy of it. We talk about sort of the large level statistics that say this many people die from this kind of cancer when we're trying to raise money for research. And that is something that animates people. The idea that just anyone dying is a bad thing. And then people tell sort of the tender heart breaking stories of their direct relations, the people that they care about in their lives dying and that being bad because they loved them so much.

And it always sort of felt weird to hate cancer because it killed someone you hated. That it had been a direct accomplice in denying you closure in some sense. Because I mean, I don't know if I would have ever come to the point of confrontation, but I would have at least had the option had cancer not taken my grandfather from this world, right? And vocalizing that to people feels strange.

It's a really, really hard thing for me to talk about because I, implicit in it is something that is sort of outside of who I normally am. I strive to be caring, I strive to love people, and to look past any faults or any perceived shortcoming. But with my grandfather I've just never been able to do that and the overriding emotion of my relationship with him was you know questioning why I and my family weren't good enough for him to stick around. Why he walked out on the possibility of our existence.

So, when cancer took him, I never got a chance to really confront him or to at least to hear some sort of justification from him. Because just in the course of normal family dialog you don't talk about my dad's stepmom and whether he regrets that decision or what happened to lead to that point. Because all I know is that my grandmother was the foundation on which not just my father's life, but my life was built.

I stand on the shoulders of giants because she worked her ass off to make sure that my dad had everything that she could give him. And why you would walk out on that woman, right? Why you would take someone who clearly was the kind of life partner that everyone would be looking for, I just don't know.

Cancer's role in that is complicated. Obviously, I've lost people that I loved. But the relationship that has been the most formative to me that cancer has ended was one of denial not one of closeness.

Do you have any siblings?

Yep, so I have two sisters. One is 18 months younger than I am and one is 5 years younger than I am.

And have you guys had any conversations about this?

Honestly, not really. I think we might have talked about it a little bit around the funeral. Like my dad sort of left town for a couple of days and-

So you guys didn't go to the funeral?

No. I forget if it was going on during a time when we had a lot to do or something. But just my dad went and we stayed in town. I honestly haven't talked to them that much about it.

What did you specifically perceive as your father's, I want to say coping process, but how did he take the news?

Well, so my dad is a really even keel person emotionally. And I wasn't there for the phone call. But I remember my dad relaying the news. Which I sort of have a parallel experience with my grandmother. When my grandmother passed, that was the only time I've ever seen my dad cry. And when my grandfather passed, it was really matter of fact. It was just super direct. It was, "Grampa Frank is dead. I'm going to the funeral. It will be in a couple of days." And then we

never really talked about it again. Other than that, I never really dug deeper on the way my father was feeling about it.

So you said you were not present when the phone call was received. Did your father know at all that his dad had cancer?

Yeah, so we all knew. And we really hadn't made any effort to go visit, especially after the diagnosis. I think we had visited maybe in the years leading up to it, but not post diagnosis we didn't really make that effort. So, we just knew that he had cancer in North Carolina seven hours away and didn't really worry about it.

Yeah. Did you ever meet him?

Yeah, so he and I, like he spent a couple of afternoons with me here and there. It was a once every three years, he and I might spend a day together. But it would be in a family setting. He didn't come to like big family gatherings or anything like that.

When you look towards the future, you look towards decisions that you're making, for example like when you're coming to college or you're doing these things, how do you think this has affected you? Do you think this has affected your life path at all?

Well, so, the grieving side of it?

Just in general, how it's affected you as a person.

Well, there's a couple of levels to that. Like there's what I have been talking about with the importance that my grandmother plays in just my being here. Like I don't think I would have these opportunities if one generation ago she hadn't been like a rock for what she had left of her family.

And then there's sort of the growing up that my dad had to do on his own. I think that that shaped who he is as a person and obviously my father has been a big part of who I am.

And then when it comes to decisions I'm making now, I'm pretty conscious of making sure I have the right people in my life. And that I'm putting, at least expressing gratitude. At least letting know that they mean something to me. Because I think that while our deeds can be complicated, sometimes words are just simple and good. I never really got that from my grandfather. You know, I got a, "Hey McKay, how ya doin'" sort of thing, but I never got a feeling of that meaning, that gratitude. So I think it's affected my M.O. in that way.

And I think going forward, the decisions I make, the people I choose to spend my time with, whoever I sort of settling down with, I think making sure that they're the right person, and really putting the time into that decision and making sure that I'm ready for that responsibility, that dedication and that I follow through on that. Because if I bring people into this world, at some level that's a choice. My kids didn't ask to have me as a dad, but I asked to have them, and making sure that I'm there for them and then there for anybody that they bring into the world. That's important to me in part because of this.

As far as like my just overall emotional profile, I don't know if this has affected it that much. But I don't know if I would, right? Generally speaking, I think I deal with grief, sadness in a really sort of Irish way. Like I think I hold it inside a lot and don't talk about it. Just try and project sort of an even keel. We never really talked about grief that much in my house in general. Even with people that were close to us when they passed. I don't think that we had big conversations about what it meant or how people were handling it.

With my mom, maybe a little bit. But especially not with my father, and I think he's my main emotional link here. So I think at least that part of my emotional growth might have been stunted. I think that my ability to cope with this and not just descend into frustration and questions and my grandfather's complicated legacy in my life, that's something that I don't like about myself and if I'm going to go through that process again with anybody else, I think that I now know that talking about it is important.

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BIOGRAPHY

Cullen Bounds was born in Pensacola, Florida on June 3, 1995, and moved with his family around the world before settling in Sanger, Texas in 2005. After graduating from Sanger High School, he enrolled in the Plan II Honors program at the University of Texas at Austin in 2013 and pursued a dual-degree in Computer Science. In college, Cullen was a Camp Texas counselor, served on the Plan II Student Association board, was an associate editor for *The Daily Texan*, was a brave of the Tejas Club, studied abroad in Botswana, and rode from Austin to Anchorage with Texas 4000. He graduated in May of 2017, and will be working as a software developer at a small company in Austin called Abilitie.